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# Development of the Patient Experience Questionnaire for Parents of Pediatric Patients (PEQP)

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**Abstract.** Patient experience (PX) is an important evaluation criterion for quality in healthcare. Compared to patient satisfaction, however less research has focused on the development of instruments to measure experiences of patients and their families. In the article, we describe the process of developing a PX questionnaire for the parents of pediatric patients in the context of children's hospital and illustrate the questionnaire items for measuring PX. The phases of the development process included retrospective interviews, description of the themes influencing PX and the metrics for measuring PX, as well as iterative development of three versions of questionnaires including data gathering and factor analysis. The final versions of the surveys suggested for implementation at the hospitals include eight PX statements for the outpatient clinic and five statements for the ward. Compared to satisfaction surveys, the developed surveys emphasize the aspects of parent's attitude towards the illness, support for families, and daily arrangements with a child patient.

**Keywords.** patient experience, children's hospital, pediatric patient, parent, questionnaire, measurement

## 1. Introduction

There is an increasing interest to apply some elements of business approach in healthcare. This includes a desire to understand how to develop high quality services and offer those to customers to improve their experience of care. For the reason, hospitals have started to collect feedback from their customers – patients. Patient feedback provides opportunities to identify and address problems and gaps in service flow and to monitor the effects of interventions [1]. Furthermore, the experiences of patients are important when evaluating the quality of healthcare services [2,3]. It has been suggested that a compact research instrument would enable monitoring of satisfaction and experiences of patients on a regular basis and thus improving the quality of healthcare services [3].

Some instruments have been developed to measure patient satisfaction [1]. Those are used to evaluate the quality of hospital care from the viewpoint of adult patients. One of the widely known instruments is HCAHPS (Hospital Consumer Assessment of

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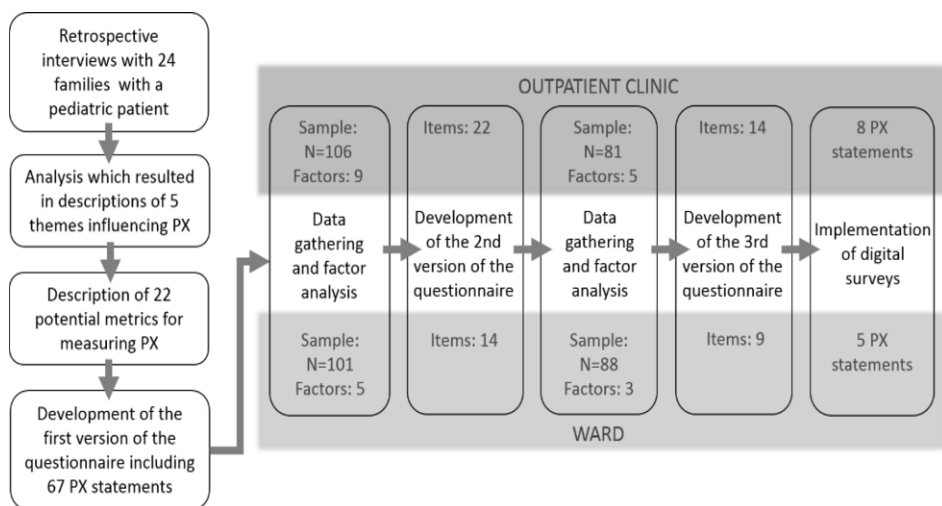
Healthcare Providers and Systems satisfaction survey) [4]. Recently, a modified version of the instrument for child patients and their families [5] was introduced. However, it is unclear whether patient satisfaction surveys actually measure satisfaction and whether the hospitals should use the results to support the development activities [4].

Compared to satisfaction, patient experience (PX) is a multidimensional and ambiguous concept [6-8] and thus, it is challenging to define and measure [9,10]. The following themes have been suggested to characterize the concept: PX is more than satisfaction alone, covers the continuum of care, focuses on expectations and individualized care, and aligns with patient-centered care principles [6].

Studies on PX of children, adolescents and their families are scarce [e.g.11]. In Finland, a research project Lapsus [12] was set to investigate the perspectives of pediatric patients and their families on hospital visits, received care and services, and the everyday life with the illness. The project was also to promote that the experiences of the families with pediatric patients to be taken into consideration when planning the services and facilities for new children's hospitals, e.g. the hospital in Helsinki [13]. The project had an approval from the ethical committee of the Helsinki University Hospital. One concrete objective was to develop instruments for measuring and monitoring PX of pediatric patients and their families while receiving hospital care. In this article, we 1) describe the process of developing a PX questionnaire for the parents of pediatric patients in the context of children's hospital, and 2) illustrate the related questionnaire items for measuring PX.

## 2. Methods

The process of developing Patient Experience Questionnaire for Parents of Pediatric Patients (PEPQ) included several phases and iterations (Figure 1).



**Figure 1.** Phases of the process of developing a PX questionnaire for the parents of pediatric patients.

Issues perceived as important and valuable by families served as a basis for developing a questionnaire. In order to map the dimensions and dynamics of PX of

families, we conducted in-depth retrospective interviews with parents having a child with a chronic illness: a cardiac or kidney disease or diabetes, juvenile rheumatoid arthritis or an inflammatory bowel disease [14]. The families were selected by the personnel of the Children’s Hospital in Helsinki. The interviews were conducted in winter 2015-2016 and each lasted 1-2 hours. Altogether 24 families participated in the interviews [15].

The analysis of the interview transcriptions yielded in identifying five themes influencing PX of families with a child patient: the success of the treatment, setup of the treatment, the healthcare personnel, coping mechanisms with the illness, support and setup of the everyday life [15,16]. For the purposes of the questionnaire development, we defined 22 preliminary metrics for PX and further created three to four statements within every metric. Thereby, the first version of the questionnaire consisted of 67 statements with a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) and ‘not applicable’ option [16].

The analysis of the interviews and particularly patient journey maps [14] indicated that different aspects of PX emerge in different phases of the patient path. These findings encouraged the development of separate PX questionnaires for hospital ward and outpatient clinic. The first versions of the questionnaires were tested in years 2016-2017 at the Children’s Hospital, Helsinki University Hospital, which is responsible to provide care for a number of different kinds of particularly severe pediatric patients from all over Finland [13]. Altogether 144 families participated in the survey study at the outpatient clinic and 119 at inpatient wards, of which 106 and 101 were included in the further analysis of the first round [15]. The data for testing the second version of the questionnaire for outpatient clinic were gathered between 01-02/2017 at the Children’s Hospital, Helsinki. In contrast, data for testing the second version for inpatient wards were gathered at the wards of three Children’s hospitals in the cities of Helsinki, Oulu and Turku between 12/2017-02/2018. At the outpatient clinic 88 responses and at the wards 93 responses were obtained, of which 81 and 88 were included in the analysis of the second round [15].

As the aim was to develop scientifically valid PX questionnaires for use at the hospitals, we applied exploratory factor analysis (EFA) as the primary method to reduce the number of the questionnaire items in each analysis round. The EFA was employed to identify latent variables underlying the questionnaire statements. In the analysis, we used Kaiser criterion and varimax rotation methods [17]. The sampling adequacy for each iteration was established using the Keiser-Meier-Olkin test (KMO) of sampling adequacy. In each round, statements with low communalities were eliminated before EFA. The key metrics for EFA for separate questionnaires and rounds are presented in Table 1.

**Table 1.** Summary of the factor analysis: rounds and key metrics for EFA.

	OUTPATIENT CLINIC		WARD	
	Round 1	Round 2	Round 1	Round 2
Original # items	67	22	67	14
Sample (N)	106	81	101	88
Cronbach’s $\alpha$	0.922	0.866	0.91	0.847
<b>Factor analysis</b>				
KMO	0.754	0.696	0.738	0.809
Factors	9	5	5	3
# items	22	14	14	9
Factor loadings	>0.5	>0.75	>0.5	>0.7
AVE (%)	81.48	79.12	79.71	77.67
Cronbach’s $\alpha$	0.888	0.821	0.840	0.884

### 3. Results

After the analysis, the third versions of the PX questionnaires included 14 and nine items. These items formed the group of suggested PX statements to be measured and monitored at the children's hospitals. However, considering the actual use of the questionnaires at the hospitals for gathering patient feedback and employing the data in improving the services, it was necessary to reduce the number of questionnaire items.

The further analysis of the questionnaire items was done based on the factor loadings and the contents of PX statements. The outpatient clinic questionnaire with 14 items consisted of seven pairs of similar statements, of which the statement with a lower loading value was excluded. In addition, it was reasonable to divide the statement about the busyness of the staff into two items concerning separately nurses and physicians. The analysis of the ward questionnaire with nine items followed the same principles: of the similar statements the one with lower loading was excluded. As the result, the final versions of the digital surveys suggested for implementation included eight PX statements for the outpatient clinic and five PX statements for the ward (Table 2). At the ward, the PX questionnaire is to be implemented as a tablet survey which is distributed to the parents before discharge. The outpatient clinic survey is to be implemented as a mobile survey and the link to the survey will be sent to the parent a day or two after their visit to the clinic.

**Table 2.** PX questionnaires for parents at outpatient clinic and at ward: PX statements and metrics.

<b>Outpatient Clinic: PX statement</b>	
<i>Answers on a five point Likert scale: Agree – Disagree</i>	<b>Metric</b>
1) The facilities and services at the Children's Hospital are well suited for treating my child's illness	Arrangements of care: Quality of the facilities and care services
2) The information and instructions received from the Children's Hospital staff have been useful	Arrangements of care: Quality of instructions received
3) The doctors have time to answer my questions	Healthcare personnel: Busyness of the staff
4) The nurses have time to answer my questions	Healthcare personnel: Busyness of the staff
5) I am confident that my child will get better or that the treatment will progress in a way that the doctors and nurses have told me	Attitude towards the illness: Confidence in recovery
6) The support and help I have received from my friends and family during my child's illness have been useful	Support and daily arrangements: Experienced quality of help received
7) My child's illness has decreased my own well-being	Support and daily arrangements: Experienced stress or burden due to illness
8) I experience fear and disbelief about my child's illness	Attitude towards the illness: Extreme emotions (anger, fear, sadness, uncertainty)
<b>Ward: PX statement</b>	
<i>Answers on a five point Likert scale: Agree – Disagree</i>	<b>Metric</b>
1) The facilities and services at the Children's Hospital are well suited for treating my child's illness	Arrangements of care: Quality of the facilities and care services
2) The facilities and services at the Children's Hospital are well suited for my family	Arrangements of care: Quality of the facilities and care services
3) I expect that my family's transition back to life at home will go smoothly	Success of care: Fluency of getting back to life at home from the hospital
4) My child's illness has decreased my own well-being	Attitude towards the illness: Experienced stress or burden due to illness
5) I experience fear and disbelief about my child's illness	Attitude towards the illness: Extreme emotions (anger, fear, sadness, uncertainty)

#### 4. Discussion

The use of patient satisfaction surveys have been criticized, since satisfaction cannot solely explain the experiences of patients [8] and surveys fit poorly for investigating the PX [e.g. 18]. In our study, we strived to overcome the applicability issues and reduce the gap between patient satisfaction and PX by developing separate questionnaires for inpatients and outpatients at the children's hospital. This allowed us to focus on the special characteristics and needs of the prevailing sections of the patient paths.

In the developed PX surveys for the ward and outpatient clinic, three statements remained common: statements about the quality of the facilities and care services, the parent's experienced stress or burden due to the illness and extreme emotions. This commonality indicates that the child's illness strongly affects the parents and the whole family. Some of the metrics in the surveys are similar to the themes of the Child HCAHPS [4]: they both involve communication, attention to safety and comfort, and the hospital environment. Compared to the satisfaction survey, our surveys emphasize the aspects of parent's attitude towards the illness and the aspects of support and daily arrangements. Hence, the surveys pay attention to the coping mechanisms of the family. The themes of our survey are aligned with the constructs of PX described by Wolf et al. [6]: patient and family perceptions, partnership and engagement.

So far, collection of PX feedback from the families of children treated in the Helsinki Children's Hospital has been sporadic at best. To this end, with the help of the Lapsus research project, not only understanding of the significance and diverse elements of PX but also the need for systematic collection of PX data have been recognized. User-friendly methods and set outcome measures, produced in the present study, are necessary for utilization of PX results in the development of healthcare processes. In the future, the instruments for collection of PX data have to be validated nationally. Next, through international collaboration it is possible to benchmark PX data between foreign children's hospitals.

The study has some limitations. The focus was on the largest children's hospitals in Finland and families of seriously and chronically ill child patients. For the ethical reasons, the participated families were selected together with the children's hospitals. Further research is needed to study the suitability of the questionnaires for different kinds of healthcare organizations and patient cases. In addition, instruments for measuring experiences of children are also needed.

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